

# FERTILITY PRESERVATION FOR MEDICAL REASONS AND REPRODUCTIVE JUSTICE

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## ABSTRACT

*This Article addresses the issues related to fertility preservation in the emerging area of fertility preservation for medical reasons using a reproductive justice framework. Fertility preservation for medical reasons refers to the process of preserving the fertility of women (and men) who need to undergo treatments that may cause reduced fertility or sterility. This process typically involves counseling a patient about the potential fertility consequences of their cancer treatment, and then if a patient so chooses (and can afford it), freezing the eggs (or sperm) to potentially use later via in vitro fertilization or using a gestational surrogate. As cancer survival rates improve, the ability to bear children after therapy is increasingly a concern for many patients. Some patients may choose their cancer therapy based on the risk of fertility loss rather than on its effectiveness to cure the cancer. Unfortunately, a patient's race and insurance status often determines if and when they are told about the fertility consequences of their treatment. Those without insurance are often already financially challenged after a cancer diagnosis, so physicians may not inform them about fertility preservation due to the high costs.*

No states currently have laws requiring insurance coverage for fertility preservation for medical reasons. Therefore, even if a patient has insurance, fertility preservation may not be covered. As a practical matter, when insurance companies deny fertility preservation coverage, there is often a short time frame between diagnosis and treatment that does not allow time to seek appeal. Those able to pay for fertility preservation for medical reasons are likely white, educated, middle- and upper-class women, similar to the population able to access general assisted reproductive technology (ART).

More recently, however, fertility preservation for medical reasons coverage has been getting more support. In June 2013, the American Medical Association (AMA) endorsed a policy that supports payment for fertility preservation and lobbies for appropriate federal legislation requiring that

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insurers pay for fertility preservation for medical reasons. This new policy treats the risk of infertility as a medical condition, not a choice, when the disease or treatment affects biological motherhood. Additionally, California is currently considering CA bill AB 912, which would require insurance companies to provide coverage for medically necessary expenses for standard fertility preservation services when a medical treatment may cause infertility. If this bill is approved, it may improve the quality of life for cancer survivors who have health insurance. Although this is encouraging, this also has the real potential to exacerbate the divide between the patient “haves” and “have-nots.”

Cancer has a disproportionately severe impact on minorities. The Centers for Disease Control and Prevention report that cancer death rates for women are highest among African Americans, followed by Caucasians, Hispanics, and Asian/Pacific Islanders. Cancer has been the leading cause of death for female Asian Americans since 1980. Some of the disproportionate impact has been attributed to delayed diagnosis as well as poor patient care. Poor people who lack health insurance or have inadequate access to quality cancer treatment also experience higher cancer incidence, higher mortality rates, and lower survival rates than their more well off counterparts.

Because fertility preservation for medical reasons is not currently covered by either private or public insurance, only those who can pay for it on their own can use it. Some scholars have argued that it should be covered by insurance. Others contend that adding fertility preservation for medical reasons to insurance coverage, without expanding health care coverage to those without insurance, may reinforce socioeconomic inequality. Additionally, an important study suggests that oncologists are less likely to discuss fertility preservation for medical reasons with African American women, regardless of income, than white women. This Article discusses this evidence and whether fertility preservation for medical reasons can be structured in a manner to promote reproductive justice. I also review fertility preservation for medical reasons with a reproductive health, reproductive rights, and reproductive fairness framework to identify normative standards for use and informed consent in fertility preservation. I conclude that more care needs to be taken to fully and properly inform vulnerable populations of their fertility preservation options. Detailed information provided to each and every patient will help build trust in the medical system that is needed to address medical and cancer disparities that exist in minority populations. Additionally, I identify other related legal issues that should be rolled into the informed consent procedure to avoid dispositional dilemmas.

#### FERTILITY PRESERVATION FOR MEDICAL REASONS AND REPRODUCTIVE JUSTICE

Orla McManus was eighteen months old when she had to undergo chemotherapy in Australia.<sup>2</sup> Understandably, her parents were worried

2. See Lucie Van Den Berg, *Orla McManus Has Had a Ground-Breaking Operation So She May Be a Mother One Day*, HERALD SUN, (July 20, 2013, 9:24 PM), <http://www.herald>

about her health and survival—but they were also worried about her future fertility.<sup>3</sup> Despite the fact that she was so young, her parents began exploring options to save their daughter's fertility.<sup>4</sup> They came across a procedure where doctors could harvest one of her ovaries, freeze the tissue, and later graft it back into Orla when she decided to have children during adulthood.<sup>5</sup> They met with a group of doctors in Melbourne who agreed to remove one of Orla's ovaries to preserve her future fertility.<sup>6</sup> Although there have been only a handful of pregnancies worldwide using grafted ovarian tissue (and one live birth to date<sup>7</sup>), Orla's parents wanted to give her a chance to have a baby when she grows up, assuming she survives her disease.<sup>8</sup>

Stories such as Orla's are going to become increasingly common due to the growth of fertility preservation for medical reasons. There has been great focus on oncofertility,<sup>9</sup> an interdisciplinary field that bridges the gap between oncology and reproductive medicine.<sup>10</sup> As survival rates for can-

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sun.com.au/news/victoria/orla-mcmanus-has-had-a-ground-breaking-operation-so-she-may-be-a-mother-one-day/story-fni0fit3-1226682509574.

3. See *id.*
4. See *id.*
5. See *id.*
6. See *id.* The Royal Children's Hospital gynecology team, who had never removed an ovary for fertility preservation from a patient so young, agreed to do the procedure due the minimal additional risk to Orla's health. See *id.* Orla was already under anesthesia for a different medically necessary procedure, and the ovary removal was done through a laparoscopic operation. See *id.*
7. See Kate Waimey Timmerman, *Research Update: First Live Human Birth From Vitrified Ovarian Tissue*, ONCOFERTILITY CONSORTIUM BLOG (Oct. 2, 2013), <http://blog.oncofertility.northwestern.edu/2013/10/research-update-first-live-human-birth-from-vitrified-ovarian-tissue-2/>.
8. See Van Den Berg, *supra* note 2. The ovary was harvested and cut into tiny slices. See *id.* The ovarian tissue was frozen and stored until Orla decides to try to start a family as an adult. See *id.* If she does, the tissue will be grafted back into her pelvic wall. See *id.* In the ideal situation, the grafted tissue will start to function and produce mature eggs, which will be removed and fertilized using in vitro fertilization. See *id.* In some cases, spontaneous pregnancy may occur after grafting. See *id.*
9. This Article uses the term "fertility preservation for medical reasons" because it includes those who may face infertility for reasons other than cancer. However, the term "oncofertility," coined by Dr. Teresa Woodruff, is often used to refer to fertility preservation for medical reasons. See *About the Oncofertility Consortium*, THE ONCOFERTILITY CONSORTIUM, <http://oncofertility.northwestern.edu/about-us> (last visited Mar. 13, 2014). In 2005, reproductive endocrinologist Dr. Teresa Woodruff founded the Oncofertility Consortium and Reproductive Endocrinology and Infertility Clinic at Northwestern University. See Jessica Reaves, *Miracle Workers*, CRAIN'S CHI. BUS., Apr. 1, 2013, at 23. The structure of the consortium serves to discuss fertility options for patients undergoing cancer treatment. See *id.* Dr. Woodruff emphasizes the importance of discussing cancer treatments and fertility "in the same breath." *Id.* Due to her policies, more than seventy-five percent of cancer patients at the Northwestern Memorial Hospital have learned about ways to save their fertility. See *id.* So far, sixty-two cancer treatment centers in the United States and ten worldwide have adopted the same procedures. See *id.*
10. See *About the Oncofertility Consortium*, THE ONCOFERTILITY CONSORTIUM, <http://oncofertility.northwestern.edu/about-us> (last visited Mar. 13, 2014). There have been stories of successful fertility preservation in the press lately. See, e.g., Jessica Reaves, *Miracle Workers*, CRAIN'S CHI. BUS., Apr. 1, 2013, at 23. One such story is that of Nicole Torrillo, who was diagnosed with ductal carcinoma at the age of 35. She

cer patients have increased over the past decades, young patients as well as adults are able to live full lives after cancer.<sup>11</sup> However, survivors often face infertility as a result of the cancer or the treatment itself.<sup>12</sup> Each patient reacts differently to treatment, and both the time available before treatment is required and the impacts of that treatment on fertility may vary.<sup>13</sup>

Fertility preservation options must be based on the patient's unique circumstances, which may be affected by a variety of issues: patient's age, marital status, religious or cultural constraints, and overall prognosis, for example.<sup>14</sup> Several traditional options as well as some newer technological options are available now for those cancer survivors who wish to have a child.<sup>15</sup> Traditional options include adoption and surrogacy, which, although allowing for a family, do not allow the women the opportunity to reproduce genetically related offspring.<sup>16</sup> Fertility preservation through the use of technology already exists for men and boys, including cryopreservation of semen for later intrauterine insemination.<sup>17</sup> For women, there currently exists the option to stimulate the ovaries to help eggs mature for retrieval and later fertilization.<sup>18</sup> However, this option often requires the delay of cancer treatments during the hormonal stimulation of the ovaries, and prepubescent girls are often not eligible for these procedures due to the immature state of their reproductive organs.<sup>19</sup> In addition, there is the potential for certain cancers to react negatively to the hormones themselves.<sup>20</sup> Thus, the field of oncofertility is trying to find new methods to both improve awareness and help find new techniques for preserving fertility.<sup>21</sup>

As advances in fertility preservation for medical reasons are made, as in other areas of reproductive technology, a number of legal and ethical issues arise.<sup>22</sup> Fertility preservation for medical reasons involves the constitutional rights of women, minors, and men to bear children, their right

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and her husband did not yet have children and as a part of her cancer treatment, she was advised of her fertility preservation options. With the help of egg freezing and in vitro fertilization, Torrillo was able to have a biological child three years after her cancer treatment. *See id.* As recently as 2005, cancer treatment options did not take into account future family planning or fertility options. *See id.* However, due to advances in modern science, Torrillo was able to secure her fertility despite undergoing cancer treatment that would leave many unable to have biological children. *See id.*

11. *See About the Oncofertility Consortium*, THE ONCOFERTILITY CONSORTIUM, <http://oncofertility.northwestern.edu/about-us> (last visited Mar. 13, 2014).

12. *See id.*

13. *See Fertility Options*, THE ONCOFERTILITY CONSORTIUM, <http://oncofertility.northwestern.edu/patients/fertility-preservation-options-nu> (last visited Mar. 13, 2014).

14. *See id.*

15. *See Gregory Dolin et al., Medical Hope, Legal Pitfalls: Potential Legal Issues in the Emerging Field of Oncofertility*, 49 SANTA CLARA L. REV. 673, 683 (2009).

16. *See id.* at 683–84.

17. *See id.* at 684.

18. *See id.*

19. *See id.*

20. *See id.* at 685.

21. *See id.* at 686.

22. *See id.* at 675.

to use assisted reproductive technology (ART), as well as feminist concerns about pressures on women to use these very technologies.<sup>23</sup> The right to reproduce is protected under both American and international law, having been reaffirmed by the United States Supreme Court<sup>24</sup> and the United Nations Universal Declaration of Human Rights, among other international covenants and conventions.<sup>25</sup>

Part I of this Article provides a description of the science of oncofertility, how cancer treatment affects fertility and how fertility can be preserved. Part II of this Article focuses on physician practice patterns related to providing information to cancer patients about fertility preservation options. Part III focuses on the American Medical Association (AMA) policy to advocate for insurance coverage of fertility preservation for medical reasons and state efforts to require such insurance coverage. Part IV of this Article reviews these policies and efforts through a reproductive justice framework to examine whether such policies even the playing field or whether they exacerbate the inequities in the health system. Finally, Part V of this Article concludes with next steps and addi-

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23. *See id.*

24. *See id.* at 676.

25. *See id.* at 677. However, it is less clear whether the right to ART is as well protected. *See id.* at 678. Although no courts have explicitly recognized a constitutional right to assisted reproduction, it would seem that the United States law "takes for granted that such a right exists." *Id.* Individual states, as well as the federal government, have adopted statutes implicitly recognizing the legality of in vitro fertilization (IVF). *See id.* at 678–79. Although these statutes do not explicitly protect the rights to IVF, they at least acknowledge that such a right exists and recognize the state and federal powers to regulate them. *See id.* at 679. The balance between the governmental power to regulate and the right to procreate is still unclear. *See id.* Courts in both in the United States and abroad have acknowledged a right to use ART, having adjudicated cases involving ownership of embryos subject to ART. *See id.* Although not explicitly noting the existence of such a right, the courts adjudicated the cases by simply treating ART as a legal means of reproduction. *See id.* at 680. Protections of the right to use ART have already been somewhat limited, as some courts have refused to enforce surrogacy contracts as against public policy, and some states have exempted insurance companies from having to cover IVF or other forms of ART. *See id.* Further, public medical assistance programs in many states do not cover infertility treatments. *See id.* In addition, women's use of various reproductive technologies is controversial as well. *See id.* at 681. Some argue that ARTs enhance a woman's choices for reproduction, while others argue that restoring fertility to female cancer patients simply puts them on equal footing with men, who can more easily store sperm for use in the future. *See id.* At the same time, others argue that ART "reinforc[es] unjust expectations about women's reproductive roles," and that some women feel the duty to under go such processes to avoid the stigma of not being able to reproduce. *Id.* Because oncofertility also works to ensure reproductive capabilities of young cancer survivors, the rights of minors to reproduce are also implicated. *See id.* at 682. While minors generally have the same reproductive rights as their adult counterparts, states have greater power to regulate these rights. *See id.* Although the Supreme Court of the United States has been more open to allowing adult involvement in a minor's decision to have an abortion, it has never allowed a parent to entirely veto such decision. *See id.* Additionally, the age of consent for a person to bear children is below the age of majority in many states, and parents cannot deprive a minor of their future reproductive ability without a court order requiring a showing of compelling need. *See id.* Overall, minors have the same constitutional protections as adults when it comes to reproduction. *See id.* at 683.

tional legal issues that must be dealt with in this emerging medico-legal field.

## I. THE SCIENCE OF ONCOFERTILITY

Oncofertility refers to the process of preserving the fertility of women (and men) who need to undergo cancer treatments that may cause reduced fertility (or sterility). This process typically involves counseling a patient about the potential fertility consequences of their cancer treatment, and then if a patient so chooses (and can afford it) freezing the eggs (or sperm) to potentially use later using in vitro fertilization or using a gestational surrogate. As cancer survival rates improve, the ability to bear children after therapy is increasingly a concern for many patients. Some patients may choose their cancer therapy based on the risk of fertility loss rather than on its effectiveness to cure the cancer. Unfortunately, a patient's race and insurance status often determines if and when they are told about the fertility consequences of their treatment. Those without insurance are often in dire straits after a cancer diagnosis, so physicians may not inform them about fertility preservation due to the high costs. In one study, four percent of women medically eligible for fertility preservation actually underwent the process.<sup>26</sup> Many options within the field of oncofertility are still experimental—especially the options for women and girls not yet of reproductive age.<sup>27</sup> These include whole ovary and oocyte cryopreservation as well as the freezing of ovarian tissue.<sup>28</sup> For boys not yet of reproductive age, and thus unable to freeze semen, investigational options include the freezing of testicular tissue.<sup>29</sup>

Chemotherapy agents and radiation therapy often result in gonadotoxicity, which can impair both male and female reproductive capabilities.<sup>30</sup> Also, some patients may require oophorectomy, or egg removal, for various benign and malignant conditions.<sup>31</sup> If a girl is past the stage of puberty, her eggs can be banked and frozen for her future use via in vitro fertilization.<sup>32</sup> The American Society of Reproductive Medicine

26. See Joseph M. Letourneau et al., *Racial, Socioeconomic, and Demographic Disparities in Access to Fertility Preservation in Young Women Diagnosed with Cancer*, 118 *CANCER* 4579, 4583 (2012), available at <http://onlinelibrary.wiley.com/doi/10.1002/cncr.26649/full>. Since 1998, the federal Woman's Health and Cancer Rights Act mandates that insurers cover breast reconstruction if they covered the mastectomy and in fact, treatment of almost every side effect from cancer treatment is covered by insurance except for fertility preservation. Dolin, *supra* note 15, at 683.

27. See Ina N. Cholst, *Oncofertility: Preservation of Reproductive Potential*, 61 *DEPAUL L. REV.* 763, 766 (2012).

28. See Mary E. Fallat & John Hutter, *Preservation of Fertility in Pediatric and Adolescent Patients with Cancer*, 121 *PEDIATRICS* e1461, e1463 (2008); Pasquale Patrizio & Arthur L. Caplan, *Ethical Issues Surrounding Fertility Preservation in Cancer Patients*, 53 *CLINICAL OBSTETRICS & GYNECOLOGY* 717, 718 (2010).

29. See Fallat, *supra* note 28.

30. See The Practice Comms. of the Am. Soc'y for Reprod. Med. and the Soc'y for Assisted Reprod. Tech., *Mature Oocyte Cryopreservation: A Guideline*, 99 *FERTILITY AND STERILITY* 37 (2013) [hereinafter "The Practice Committees"].

31. See *id.* at 41.

32. See *id.* at 39. "Data on pregnancy and live births from oocyte cryopreservation in cancer patients are very limited, and success rates must be extrapolated from other

determined that such egg freezing was no longer an experimental procedure.<sup>33</sup> Freezing eggs and sperm have been good options for postpubertal cancer patients or other patients unable or not wishing to cryopreserve embryos.<sup>34</sup> However, to date, there have been no long- or even short-term studies on the viability of ovarian tissue cryopreservation. Because the population being offered fertility preservation is suffering from cancer, the predicted prognosis of the patient will determine whether fertility preservation is a viable option. If the cancer must be treated immediately, there may be no time to delay treatment to undergo fertility preservation. Because African Americans often have their illness detected at a later stage than other populations, their prognosis is often worse.<sup>35</sup> Other limitations to use of this technology include age, cost, and how available it is in the patient's area.<sup>36</sup>

Fertility often cannot be spared when reproductive organs must be entirely removed, when the radiation field is located such that reproductive organs cannot be shielded, or when chemotherapy must be administered directly to the reproductive organs of either male or female patients.<sup>37</sup> The most common reason for decreased fertility after cancer treatment is due to exposure to uterine radiation, hypothalamic/pituitary radiation, or alkylating agent chemotherapy.<sup>38</sup> One study has shown that

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populations for patient counseling. However, in this population at high risk for infertility, oocyte cryopreservation may be one of the few options available and therefore is recommended with appropriate counseling." *Id.* at 41.

33. *See id.* at 41.

34. *See id.*

35. Stacey A. Missmer et al., *Cultural Factors Contributing to Health Care Disparities Among Patients with Infertility in Midwestern United States*, 95 FERTILITY & STERILITY 1943, 1943 (2011).

36. *See id.*

37. *See* Cholst, *supra* note 27, at 764.

38. *See* Daniel M. Green et al., *Fertility of Female Survivors of Childhood Cancer: A Report from the Childhood Cancer Survivor Study*, 27 J. OF CLINICAL ONCOLOGY 2677, 2681 (2009), available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2690392/>. There have been several studies on fertility preservation in breast cancer patients. When discussing fertility preservation for medical reasons, it is important to note that improved early detection and treatment has increased the likelihood that women diagnosed with early-stage breast cancer will survive their disease. *See* Pamela N. Munster, *Fertility Preservation and Breast Cancer: A Complex Problem*, CANCER NETWORK (June 17, 2013), <http://www.cancernetwork.com/display/article/10165/2145852>. Whether a girl or woman will become infertile during treatment depends on many factors including patient's age at diagnosis, the type and dose of regimen used, genetic predisposition, and lifestyle factors. *See id.* An increasing number of young patients with breast cancer have never conceived or completed family planning at diagnosis of breast cancer. *See id.* Age at diagnosis and at the anticipated completion of therapy of breast cancer are the most important natural factors when considering fertility preservation, especially when there are an increasing number of children born to women over the age of 35. *See id.* Fifteen out of one thousand children in the United States were born through the use of assisted reproductive technology (ART) in 2011, assisting in the delayed onset of childbearing. *See id.*; Brady E. Hamilton et al., *Births: Preliminary Data for 2011*, NAT'L VITAL STATS. REPS., Oct. 3, 2012, at 1. Fertility is strongly linked to the onset of menopause with a steady decrease in ovarian reserve and fertility after age thirty, with a sharp drop after age thirty-seven. *See generally* M.J. Faddy et al., *Accelerated Disappearance of Ovarian Follicles in Mid-Life: Implications for Forecasting Menopause*, 7 HUMAN REPROD.

although cancer survivors take a longer time to get pregnant, sixty-four percent of them with self-reported infertility achieved a pregnancy.<sup>39</sup> This study brings some hope that cancer survivors may be able to become pregnant even without fertility preservation.<sup>40</sup>

Amenorrhea, or a lack of menstruation related to cancer therapy, can also lead to fertility problems. This symptom is dependent on agent used, dose, and duration of therapy and is strongly associated with advancing age.<sup>41</sup> Some studies show that chemotherapy-induced amenorrhea could be considerably reversed in time.<sup>42</sup>

Fertility preservation is an important topic, but even when physicians discuss the risk of cancer therapy on fertility, patients are not referred to a reproductive center with expertise in cancer because of perceived risks,

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1342, 1342–46 (1992). Underlying risk factors, like premature or early menopause (before age 45) impacted by family history, smoking, ethnicity, and socioeconomic status, should be considered in each patient with assessing risk of chemotherapy-induced amenorrhea and the potential for successful fertility preservation. See generally Ellen B. Gold et al., *Factors Associated with Age at Natural Menopause in a Multiethnic Sample of Midlife Women*, 153 AM. J. EPIDEMIOLOGY 865, 865–74 (2001).

39. See Green et al., *supra* note 38. The Childhood Cancer Survivor Study (“CCSS”) studied individuals who survived five or more years after a cancer diagnosis, treated in twenty-seven different institutions, both in Canada and the United States. See *Learn More*, CHILDHOOD CANCER SURVIVOR STUDY (CCSS), <https://ccss.stjude.org/about/learn-more> (last visited Apr. 9, 2014). Compared to their non-cancer survivor siblings, the survivors had an increased risk of clinical infertility and less likely to be prescribed drugs for treatment of infertility, despite being equally likely to seek such drugs. See Green et al., *supra* note 38.

40. See Green et al., *supra* note 38. See also Stella M. Davies, *Subsequent Malignant Neoplasms in Survivors of Childhood Cancer: Childhood Cancer Survivor Study (CCSS) Studies*, 48 PEDIATRIC BLOOD CANCER 727 (2007); A.C. Mertens, *Cause of Mortality in 5-Year Survivors of Childhood Cancer*, 48 PEDIATRIC BLOOD CANCER 723 (2007); Leslie L. Robison, *Treatment-Associated Subsequent Neoplasms Among Long-Term Survivors of Childhood Cancer: The Childhood Cancer Survivor Study Experience*, PEDIATRIC RADIOLOGY, Feb. 2009 (Supp. 1), at S32; Leslie L. Robison et al., *The Childhood Cancer Survivor Study: A National Cancer Institute-Supported Resource for Outcome and Intervention Research*, 27 J. CLINICAL ONCOLOGY 2308 (2009); Gregory T. Armstrong, *Long-Term Survivors of Childhood Central Nervous System Malignancies: The Experience of the Childhood Cancer Survivor Study*, 14 EUROPEAN J. PEDIATRIC NEUROLOGY 297 (2010).

41. See Munster, *supra* note 38.

42. See *id.* There was once concern over artificially creating high estrogen levels during ovarian stimulation, but studies have suggested that ovarian stimulation can be safely accomplished with aromatase inhibitors or tamoxifen, preventing high estradiol peaks during ovarian stimulation. See *id.*; Kutluk Oktay et al., *Fertility Preservation in Breast Cancer Patients: A Prospective Controlled Comparison of Ovarian Stimulation With Tamoxifen and Letrozole for Embryo Cryopreservation*, 23 J. CLINICAL ONCOLOGY 4347, 4347–53 (2005). This process can be completed within one menstrual cycle, it is feasible prior to initiation of chemotherapy, and ART does not require women to have a partner at the time of diagnosis to complete in vitro fertilization (IVF) for a later pregnancy. See *id.* at 4348. The delay of pregnancy may not be detrimental when donor oocytes or frozen embryos or oocytes are used because only the age of the oocytes, but not the age of the uterus, appears to be a factor in the ability to conceive. See Munster, *supra* note 38. When using non-donor oocytes, the rate of births resulting from ART is linked to age of the patient at time of harvest. See *id.* When donor oocytes are used, age, ovarian reserve, and ovarian function are no longer limiting factors. See Barbara Luke et al., *Cumulative Birth Rates With Linked Assisted Reproductive Technology Cycles*, 366 NEW ENG. J. MED. 2483, 2483–91 (2012).



cost, and time constraints.<sup>43</sup> The relevance of fertility preservation is not a high priority upon diagnosis, but becomes more important once the patient's prognosis improves.<sup>44</sup> Another study determined that loss of fertility resulted in a detriment to patients' quality of life, and counseling about fertility loss and discussion of fertility preservation options resulted in better long-term acceptance of fertility loss.<sup>45</sup>

## II. CURRENT PRACTICE PATTERNS

Many oncologists are not following fertility preservation guidelines and are unaware of current guidelines regarding fertility preservation for cancer patients, according to the results of a survey presented at the American Society of Clinical Oncology ("ASCO") Annual Meeting.<sup>46</sup> In 2006, ASCO issued guidelines regarding fertility preservation,<sup>47</sup> which recommended that oncologists "address the possibility of infertility with patients treated during their reproductive years and be prepared to discuss possible fertility preservation options or refer appropriate and interested patients to reproductive specialists."<sup>48</sup> However, only 38% of the surveyed physicians stated that they were aware of ASCO's guidelines regarding infertility.<sup>49</sup> Among oncologist respondents, the majority (79%) reported discussing fertility preservation with patients of childbearing age, however, 75% of that group failed to refer such patients to reproductive specialists or distribute educational materials regarding fertility preservation.<sup>50</sup> Although, according to one study, at least half of patients do not recall receiving information about fertility from their physicians,<sup>51</sup> there is wide variation in the information that is disseminated. It can range from a brief mention about the risk for infertility to an in-depth discussion about the risks for impaired fertility and referrals to reproductive endocrinologists. Physicians reported that the primary barrier to discussion was a patient being too ill to delay treatment. Many respondents also said that they did not discuss fertility preservation when they believed that the patient had a poor prognosis.<sup>52</sup> Additionally, the ASCO guidelines do not oblige physicians to discuss fertility preservation with

43. See Gwendolyn P. Quinn et al., *Discussion of Fertility Preservation with Newly Diagnosed Patients: Oncologists Views*, 1 J. CANCER SURVIVORSHIP 146, 146 (2007).

44. See Munster, *supra* note 38.

45. See *id.*; Joseph M. Letourneau et al., *Pretreatment Fertility Counseling and Fertility Preservation Improve Quality of Life in Reproductive Age Women With Cancer*, 118 CANCER 1710, 1710 (2012). Thus, just having a physician inform a patient of their fertility preservation options seems to help, even when the patient does not utilize such options. See *id.* at 1715.

46. See Roxanne Nelson, *ASCO 2009: Fertility Preservation Guidelines Not Widely Followed*, MEDSCAPE.COM (June 1, 2009), <http://www.medscape.com/viewarticle/703634>.

47. See Stephanie J. Lee et al., *American Society of Clinical Oncology Recommendations on Fertility Preservation in Cancer Patients*, J. OF CLINICAL ONCOLOGY 2917, 2927. (2006).

48. *Id.* at 2917.

49. See Nelson, *supra* note 46.

50. See *id.*

51. See *id.* at 2926.

52. See Am. Soc'y for Reprod. Med., *Fertility Preservation for Cancer Patients: Demographic Disparities in Counseling and Financial Concerns are Barriers to Utilization*, IVF.NET (Oct. 23, 2012), <http://www.ivf.net/ivf/fertility-preservation-for-cancer-patients->

patients; they simply make the recommendation that physicians should do so.

A concern often cited by physicians about why they do not always discuss fertility preservation is the cost involved in trying to preserve fertility. Because insurance companies do not have to cover fertility preservation for medical reasons, it is often an additional financial burden in an already stressful time. An important barrier identified by both patients and clinicians is the high cost and the lack of insurance coverage for fertility preservation services. In one study, researchers examined state policies regarding insurance coverage as it related to infertility in cancer patients. Although fifteen states have laws relating to insurance coverage for infertility or IVF procedures, none of them have laws or regulations addressing insurance coverage for fertility preservation methods specific to cancer patients.<sup>53</sup> Arguably, even in states that do not generally endorse insurance coverage fertility preservation generally, there may be more political will and empathy from the general public to require coverage for patients who lose their fertility due to cancer treatment.

One study showed that females, Blacks, and the uninsured were all much less likely to be told about fertility preservation during the course of their cancer therapy.<sup>54</sup> Of these groups, it appears that females with government insurance were at the highest risk for not having discussions about fertility preservation.<sup>55</sup> Not surprisingly, uninsured status was a predictor for not making preservation arrangements prior to starting cancer treatment within all of the groups.<sup>56</sup>

Another study similarly found that many cancer patients may not be receiving counseling about their treatment's potential to affect their long-

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demographic-disparities-in-counseling-and-financial-concerns-are-barriers-to-utilization-06988.html.

53. See David Orentlicher, *Discrimination Out of Dismissiveness: The Example of Infertility*, 85 IND. L.J. 143, 168–69 (2010).

54. See Margaret Shnorhavorian et al., Fertility Preservation Among Adolescent and Young Adult Cancer Survivors in the AYA Hope Study, American Urological Association National Meeting, Society of Pediatric Urology (May 3, 2013), available at <http://www.spuonline.org/abstracts/2013/8.cgi>. One study examined adolescents and young adults ("AYA") with cancer and the devastating effect that treatment could have on future fertility. See *Overview and Key Objectives*, ADOLESCENT & YOUNG ADULT HEALTH OUTCOMES & PATIENT EXPERIENCE STUDY (AYA HOPE) (last updated Sept. 13, 2013), <http://appliedresearch.cancer.gov/surveys/aya/overview.html>. Funded by the National Cancer Institute and the Lance Armstrong Foundation, the facilitators of this study, called the AYA HOPE Study, investigated factors associated with fertility preservation and cancer treatment effects on the female reproductive system. See *id.* at 484. Patients, male and female, all diagnosed with cancer between 2007 and 2009, were told by their healthcare providers that cancer treatments may affect their fertility. See Shnorhavorian, *supra* note 54. In addition, they all discussed fertility preservation options with their doctors and made arrangements for such. See *id.* The issue to be determined was whether fertility preservation measures were associated with demographic characteristics such as race and marital status, and socioeconomic factors such as education and employment status. See *id.* Provider and hospital features were also taken into consideration. See *id.*

55. See *id.*

56. See *id.*

term reproductive health and that demographic disparities exist between those who receive counseling and those who do not.<sup>57</sup> Factors that influenced who got counseling and who did not included education level, whether or not the women had children, and insurance status.<sup>58</sup> Women who had already had children at the time of their treatment were half as likely to be counseled about fertility preservation as those who were childless.<sup>59</sup> Just because a woman has already had a child does not mean that she should not be counseled about the option to preserve her fertility should she decide to have additional children. The patient should make this decision, not the physician. However, it appears that physicians are either consciously or subconsciously withholding this information from women who have already had children prior to their cancer diagnosis. Women who had bachelor's degrees were twice as likely to be counseled as those without a degree and women with private insurance were three times more likely to receive counseling than the uninsured.<sup>60</sup>

An additional survey-based investigation suggests "that a lack of money is the biggest barrier preventing women with cancer who have received counseling on fertility preservation from following through with it."<sup>61</sup> Ninety percent of women surveyed who had received counseling reported at the time for decision-making that cost and lack of insurance coverage were their reasons for not utilizing fertility preservation technologies.<sup>62</sup> Additional surveys have found that men are generally counseled in fertility preservation less frequently than women, with only 30% of clinics surveyed even offering counseling to male patients.<sup>63</sup> Preliminary results show that, of patients who received cancer treatment with the power to impact their fertility, only 50% were counseled by their oncology team about those risks, and only 3% underwent fertility preservation.<sup>64</sup>

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57. Am. Soc'y for Reprod. Med., *supra* note 52 (the survey was mailed to 2300 women from the California Cancer Registry who had been diagnosed with a gynecologic cancer between 1993 and 2007 and aged 18 to 40 at time of their diagnosis).

58. *See id.*

59. *See id.*

60. *See id.*

61. *Id.* (citing Joseph M. Letourneau et al., *Sociodemographic Disparities Affect Access to Reproductive Health Counseling Among Reproductive Age Women Undergoing Gynecologic Cancer Treatment*, FERTILITY & STERILITY, Sept. 2012 (Supp.), at S121. The average cost for oocyte cryopreservation is \$6608; embryo cryopreservation, \$8285; sperm cryopreservation, \$244; and sperm storage, \$381 annually. *See id.* (citing Erin E. Niemasik et al., *It All Comes Down to Money: Why Women Decide Not to Undergo Fertility Preservation*, American Society for Reproductive Medicine (Oct. 2012)).

62. *See id.*

63. *See id.*

64. *See id.*

### III. EFFORTS TO PROMOTE FERTILITY PRESERVATION FOR MEDICAL REASONS

#### *AMA Policy on Fertility Preservation in Cancer*

In June 2013, the American Medical Association adopted a policy “support[ing] coverage by all insurance providers of fertility preservation therapies for patients requiring cancer treatments that may result in infertility.”<sup>65</sup> Currently insurers do not routinely cover these fertility treatments, which the AMA says, “should be an essential part of the management of [a patient’s] cancer.”<sup>66</sup> In addition, the new policy supports lobbying for federal legislation.<sup>67</sup> The new policy would essentially treat infertility as a side effect of treatment or as a condition unto itself created by cancer.<sup>68</sup> Thus, it is not the patient solely choosing to undergo infertility treatments for their own sake, but rather the need for the treatments is a result of the medical condition.

#### *Other Medical Associations’ Policies*

The guidelines from the National Comprehensive Cancer Network and the American Society of Clinical Oncology similarly note that infertility from cancer treatments must be discussed and the fertility preservation should be offered to anyone affected by those treatments.<sup>69</sup>

Some advocates for insurance coverage for fertility preservation compare it to mandated insurance coverage for breast reconstruction after breast cancer.<sup>70</sup> The Women’s Health and Cancer Rights Act of 1998 mandated that if insurers covered mastectomy, then they must also cover breast reconstruction.<sup>71</sup> Every side effect of cancer treatment is covered by insurance except for infertility—often because the individual has not yet been “diagnosed with infertility.”<sup>72</sup>

Several arguments may be made as to why breast reconstruction and other conditions resulting from cancer, such as hair loss, should be

65. Press Release, Am. Med. Ass’n, AMA Adopts New Policies on First Day of Voting at Annual Meeting (June 17, 2013), available at <http://www.ama-assn.org/ama/pub/news/news/2013/2013-06-17-new-ama-policies-annual-meeting.page> [hereinafter AMA Press Release].

66. *Id.*

67. See Angela Krausfeldt, *Support for Fertility Preservation is Now an AMA Policy!*, ONCOFERTILITY CONSORTIUM BLOG (June 28, 2013), <http://blog.oncofertility.northwestern.edu/2013/06/support-for-fertility-preservation-is-now-an-ama-policy/>.

68. *See id.*

69. See Raphael Yechieli, *Triaging Fertility Preservation & the AMA*, TRIAGE CANCER BLOG (July 1, 2013), <http://triagecancer.org/blog/triaging-fertility-preservation-the-ama/>; Stephanie J. Lee et al., *American Society of Clinical Oncology Recommendations on Fertility Preservation in Cancer Patients*, 24 J. OF CLINICAL ONCOLOGY 2917 (2006) (advocating that, as a part of treatment discussions and informed consent, fertility preservation options should be discussed by the oncologist, or the patient should be referred to a reproductive specialist).

70. *See Yechieli, supra note 69.*

71. *See id.*

72. *Id.*

treated differently as compared to the treatment for infertility.<sup>73</sup> First, several ARTs are still considered experimental, and insurers generally do not cover experimental procedures.<sup>74</sup> Alternately, breast reconstruction is already considered an established procedure.<sup>75</sup> Second, most insurance companies cover conditions that currently exist or that have a more clear certainty of existing.<sup>76</sup> Because infertility is only a future possibility, and the chances that some patients will even experience infertility may be low, most insurance companies are unlikely to cover the procedures.<sup>77</sup> In addition, even after a patient undergoes most methods used to preserve fertility, such as cryopreservation, the embryos, eggs or ovarian tissue may not actually be used for some time into the future.<sup>78</sup> Third, items such as breast reconstruction or wigs are often covered by insurance because they are visible to the patient and those around them, and are thus seen as necessary to help normalize the patient's physical body and gender.<sup>79</sup> Fourth, fertility preservation is a more complex issue than other side effects or conditions because it ultimately affects not just the patient, but also their partner, family and future offspring.<sup>80</sup> This is especially complex in cases where family members seek to use preserved eggs, sperm or embryos may be used for posthumous reproduction, after a cancer patient loses his or her battle against the disease.

To counter these potential arguments against coverage of fertility treatments, it can be argued that many in the scientific community no longer consider many fertility preservation treatments to be experimental.<sup>81</sup> In fact, as the American Society for Reproductive Medicine concluded that oocyte cryopreservation "should no longer be considered experimental."<sup>82</sup> Egg freezing is also now more commonplace, with up to 70–90% of eggs surviving the freeze-thaw process.<sup>83</sup>

Additionally, just because infertility may not be immediate and may not affect a patient until years down the road when they are prepared to start a family, it does not make the harm any less real or significant.<sup>84</sup> Further, while breasts and hair are visible signs of femininity, pregnancy and the bearing of children can be considered the ultimate sign of femininity.<sup>85</sup> And, finally, insurance companies already cover other proce-

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73. See Lisa Campo-Engelstein, *Insurance Coverage for Cancer Treatment-Induced Conditions: Comparing Fertility Preservation Technology and Breast Reconstructive Surgery*, 61 DEPAUL L. REV. 849, 855 (2012).

74. See *id.* at 856. Currently, fertility preservation techniques are in the experimental stage. However, even if they become more established, insurance companies do not cover fertility preservation. However, some ART clinics do offer discounts to cancer patients, compared with other infertile patients.

75. See *id.*

76. See *id.*

77. See *id.*

78. See *id.*

79. See *id.* at 857.

80. See *id.*

81. See *id.* at 856.

82. See The Practice Committees, *supra* note 30, at 37.

83. See *id.* at 39.

84. See Campo-Engelstein, *supra* note 73, at 857.

85. See *id.*

dures that have complex implications for those other than simply the patient—fetal surgery, including “corrective” surgery for intersex infants, and genetic testing for hereditary diseases.<sup>86</sup> The complexity of the issue should not mean that a patient is precluded from coverage, but simply that additional counseling and assistance be provided.<sup>87</sup>

### *Bills Mandating Insurance Coverage of Fertility Preservation*

Although no states currently have laws requiring insurance coverage for fertility preservation for medical reasons, as of January 2013, the following states mandate insurance coverage for general infertility treatments—Arkansas, California, Connecticut, Hawaii, Illinois, Louisiana, Maryland, Massachusetts, Montana, New Jersey, New York, Ohio,<sup>88</sup> Rhode Island, Texas, and West Virginia.<sup>89</sup> These laws are often inconsistent in terms of what type of infertility services are covered, whether marital status is an issue, and whether there is a maximum age of coverage.<sup>90</sup> Only Connecticut, Illinois, Maryland, Massachusetts, Montana, New Jersey, Ohio, and West Virginia require insurers to cover IVF at the time of this writing. California law mandates that some insurance coverage at least be offered to cover infertility treatments, but does not require IVF to be covered.<sup>91</sup> Massachusetts’ mandate, although not specifically aimed at infertility due to cancer treatments or other medical diagnoses, is a bit more flexible than other states in that it has a built in review system that

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86. *Id.*

87. *See id.*

88. OHIO REV. CODE ANN. § 1751.01(A)(1)(h) (West 2013) (requiring health maintenance organizations (HMOs) to provide infertility services, when medically necessary). It is not at all clear how medically necessary would be interpreted when someone needs to undergo chemotherapy and may face infertility as a result. It is unclear and arguably unlikely that insurer would consider it medically necessary for such a patient to receive fertility preservation services prior to the chemotherapy.

89. *State Laws Related to Insurance Coverage for Infertility Treatment*, NAT’L CONFERENCE OF STATE LEGISLATURES, <http://www.ncsl.org/issues-research/health/insurance-coverage-for-infertility-laws.aspx> (last updated Mar. 2012). *See also* Ark. Code Ann. §§23-85-137 (West 2011), 23-86-118 (West 2012); CAL. HEALTH & SAFETY CODE §1374.55 (West 2012); CAL. INS. CODE §10119.6 (West 2012); CONN. GEN. STAT. §38a-536 (2013); HAW. REV. STAT. §431:10A-116.5(a) (2012); MASS. GEN. LAWS ANN. ch. 175, §47H (West 2010), 176A §8K (West 2010), 176B §4J (West 2010), 176G §4 (West 2011); MD. CODE ANN., INS. §15-810 (West 2012); MONT. CODE ANN. §33-31-102 (West 2011); N.J. STAT. ANN. §17B:27-46.1x (West 2001); N.Y. INS. LAW §§3221(k)(6), 4303(s) (McKinney 2012); OHIO REV. CODE ANN. §1751.01 (West 2012); R.I. GEN. LAWS §§27-18-30, 27-19-23, 27-20-20, 27-41-33 (2012); TEX. INS. CODE ANN. art. 1366.005 (West 2005); W. VA. CODE §33-25A-2 (2010).

90. *See* Briana K. Fundalinski, *Limitations on Insurance Coverage For Fertility Treatment: Arguments For & Against Capping the Age & Restricting the Marital Status*, 23 Alb. L.J. Sci. & Tech. 625, 629.

91. *See, e.g.,* CAL. HEALTH & SAFETY CODE § 1374.55; CAL. INS. CODE § 10119.6 (specifying insurance for certain forms of infertility treatment, but not IVF); Susan T Vadaparampil, *State Laws and Regulations Covering Fertility Preservation for Cancer Patients*, 2009 ASCO ANNUAL MEETING (Sept. 21, 2013), <http://meetinglibrary.asco.org/content/35754>.

allows additional infertility procedures to be covered as they move from research phases into routine procedures.<sup>92</sup>

Many states do not clearly define what is meant by infertility.<sup>93</sup> For those states that do define infertility—California, Connecticut, Illinois, Massachusetts, New Jersey, New York, and Rhode Island—all definitions include the inability to conceive after a year or more of sexual relations.<sup>94</sup> Therefore, in order to be covered by insurance, individuals must have been trying to conceive. Further, other definitions include requirements that the individual be married, have different timeframes for men and women, or require specific diagnosis by physician of a condition as the cause of the infertility.<sup>95</sup> Even the definition of infertility from the American Society for Reproductive Medicine is limited to those who have been unable to conceive after having engaged in consistent unprotected sex for one year.<sup>96</sup> The World Health Organization similarly defines infertility as “[a] disease of the reproductive system defined by the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse,” as does the National Institute of Health.<sup>97</sup> Thus, even where insurance coverage may be mandated for fertility treatments, it does not necessarily cover patients with cancer who are seeking fertility preservation prior to treatment. These patients have not been unable to conceive yet and because fertility preservation seeks to prevent a future and not present harm, without a definitional change, these patients would likely not be considered infertile under these laws.

Connecticut,<sup>98</sup> Hawaii,<sup>99</sup> New Jersey,<sup>100</sup> and California<sup>101</sup>—as well as the United States Congress<sup>102</sup> have had bills pending relating to insurance coverage fertility preservation specifically relating to patients with cancer or cancer treatments. California’s bill was approved by the assembly in May 2013 and was set to be heard by the senate in July 2013.<sup>103</sup> California’s bill would require a health care service plan and a health insurer to provide, on a large group basis, coverage for medically necessary expenses for standard fertility preservation services “when a necessary

92. See Daniel Basco et al., *Insuring Against Infertility: Expanding State Infertility Mandates to Include Fertility Preservation Technology for Cancer Patients*, 38 J. L. MED. & ETHICS 832, 833 (2010).

93. See Vadaparampil, *supra* note 88.

94. See *id.*

95. See *id.*

96. See Basco et. al., *supra* note 89, at 832.

97. *Id.* at 834.

98. H.B. 5644, Gen. Assemb., Jan. Sess. (Conn. . 2013).

99. H.B. 2105, 26th Leg., Reg. Sess. (Haw. 2012).

100. A.B. 2479, 215th Leg., 1st Sess. (N.J. 2012).

101. A.B. 912, 2013-2014 Assemb., Reg. Sess. (Cal. 2013). An identical version of this proposed legislation was struck down in 2011. See A.B. 428, 2011-2012 Assemb., Reg. Sess. (Cal. 2011); see also Lisa Campo-Engelstein, *Insuring Against Infertility*, TRIAGE CANCER BLOG (Aug. 20, 2012), <http://triagecancer.org/blog/insuring-against-infertility/>.

102. H.R. 1851, 113th Cong. (2013). S. 881, 113th Cong. (2013).

103. See Krausfeldt, *supra* note 64.

medical treatment may directly or indirectly cause iatrogenic infertility to an enrollee or insured.”<sup>104</sup>

Although some may laud the goal of insurance coverage for fertility preservation, these legislative efforts raise many questions about who will benefit from these laws. What about those without insurance? Will this exacerbate the gap between the insured and uninsured (or underinsured) even more? Will minorities and the poor even benefit from this technology? Is it more likely that richer white cancer patients will be able to preserve their biological connections to future children via fertility preservation while minority cancer patients may be faced with fewer reproductive options? In the next Part of this Article, I analyze these issues through a reproductive justice framework to try to answer these questions in a thoughtful and inclusive manner.

#### IV. A REPRODUCTIVE JUSTICE ANALYSIS OF FERTILITY PRESERVATION FOR MEDICAL REASONS

This Article has thus far described medical advances, regulatory efforts, and medical group policies promoting fertility preservation for medical reasons. This Part analyzes whether this new technology should be promoted and whether its normative use should be an ideal. I use a reproductive justice framework to highlight that policies and legal requirements advocating fertility preservation education amongst cancer patients do not affect all individuals equally. Minorities, African-Americans especially, have poorer rates of cancer survival than whites. Because fertility preservation counseling is left up to the discretion of the physi-

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104. A.B. 912, 2013-2014 Assemb., Reg. Sess. (Cal. 2013). The fiscal effect of AB 912 was analyzed by the fiscal committee and reported on May 25, 2013. *AB 912 Assembly Bill – Bill Analysis*, OFFICIAL CALIFORNIA LEGISLATIVE INFORMATION, [http://www.leginfo.ca.gov/pub/13-14/bill/asm/ab\\_0901-0950/ab\\_912\\_cfa\\_20130525\\_030716\\_asm\\_floor.html](http://www.leginfo.ca.gov/pub/13-14/bill/asm/ab_0901-0950/ab_912_cfa_20130525_030716_asm_floor.html) (last visited Apr. 9, 2014). They found that the bill will result in approximately \$69,000 of additional costs to the California Public Employees’ Retirement System for additional premiums and unknown costs, potentially greater than \$100,000, to Covered California, to the extent the fertility treatment preservation services exceed the Essential Health Benefits (EHB) requirement under the Affordable Care Act (ACA). *See id.* Mandated-benefit laws require an insurer to provide a certain kind of benefit to cover a specified illness or procedure whenever someone purchases a certain kind of insurance. *See Metro. Life Ins. Co. v. Massachusetts*, 471 U.S. 724, 728 (1985). When legislation enacts mandated-benefit laws, issues of pre-emption emerge. It is likely that these mandated-benefit laws would not be preempted by either the federal Employee Retirement Income Security Act of 1974 (ERISA) or the National Labor Relations Act (NLRA). The Supreme Court and Sixth Circuit have seen cases similar to the one at bar, ruling on legislature requiring health insurance providers to provide minimum health benefits. *See id.* at 727–28. The Sixth Circuit found a statute requiring every insurer to offer health insurance policies within the state to provide coverage for substance abuse to be a mandated-benefit law. *See Mich. United Food & Comm. Workers Unions v. Baerwaldt*, 767 F.2d 308, 310, 312 (6th Cir. 1985). It would be undisputed within the courts that the new AMA policy and the California bill would both be considered mandated-benefit laws. Legislation that requires insurance providers to provide the benefit of fertility preservation therapies will likely be considered a mandated-benefit law, just as requiring insurers to provide mental health care and substance abuse was found to be in the Supreme Court and the Sixth Circuit.



cian, often those with poorer prognoses, such as African-Americans, are not informed of their choices. I hope to identify the gaps that exist in current proposals and suggests areas of focus for fertility preservation for medical reasons.

### *What is Reproductive Justice?*

About three decades ago, the reproductive justice movement began as a response to the feminist conception of reproductive rights as being “pro-choice.”<sup>105</sup> Women of color in the United States who were working with grassroots feminist organizations spearheaded the effort to align reproductive rights with social justice—and acknowledge that often poor, women of color do not have the same choices as other women.<sup>106</sup> Sister-Song Women of Color Reproductive Health Collective, coined the term “reproductive justice,” and was modeled upon global women’s health movements. Reproductive justice takes as its starting point women’s real-life experiences with reproductive oppression in their communities. Such oppression includes history of forced sterilization, high-risk contraception, and environmental factors that resulted in diminished reproductive health.<sup>107</sup> Historically reproductive health has been defined from the standpoint of white American women’s struggle for access to contraception and abortion.<sup>108</sup> A reproductive justice analysis widens the conversation and focuses on all-encompassing long-term ends: better lives for women, healthier families and sustainable communities. Reproductive justice will be achieved only when women and girls have the economic, social and political power and resources to make healthy decisions about their bodies, sexuality and reproduction for themselves, their families and their communities in all areas of their lives. I will examine how fertility preservation for medical reasons ties into the goal of reproductive justice.

In this Part, I attempt to create a framework to analyze fertility preservation for medical reasons through a reproductive justice lens. To that end, first I focus on the health aspects of this technology. Next, I focus on fertility preservation for medical reasons through a reproductive rights perspective. Finally, I analyze this technology through a fairness perspective. Through this framework, I unpack how increasing access to fertility preservation for medical reasons, as well as increasing access to health care in general, helps poor and minority women overcome class and power disadvantages to achieve reproductive justice.

### *Fertility Preservation for Medical Reasons and Health*

The reproductive health component of a reproductive justice model traditionally focuses on women’s access to reproductive health services.<sup>109</sup> It emphasizes the importance of women’s access to, and understandings

105. See Zakiya Luna, *From Rights to Justice: Women of Color Changing the Face of US Reproductive Rights Organizing*, 4 SOCIETIES WITHOUT BORDERS 343, 350–51 (2009).

106. See *id.* at 358.

107. See *id.*

108. See Sarah London, *Reproductive Justice: Developing a Lawyering Model*, 13 BERKELEY J. AFR.-AM. L. & POL’Y 71, 82 (2001).

109. See *id.* at 76.

of, medical services such as pap smears, pre- and post-natal care, abortion services and counseling, family planning, access to safe and effective contraception, and other sexually transmitted infections.<sup>110</sup> It closes health disparities through the creation of clinics, educational outreach, and agencies designed to provide women with a full range of affordable, culturally sensitive, health services. But true reproductive justice should look at the whole health of a woman, and not just the reproductive potential. In this section, I consider the whole health of the individual, not just reproductive health.

When examining fertility preservation for medical reasons, the disparities in medical outcomes for minorities must be acknowledged. African Americans are behind in terms of life expectancy and infant mortality compared with other populations.<sup>111</sup> Generally, ethnic minorities have less access to healthcare and have a poorer health status overall.<sup>112</sup> Also, African Americans face a greater risk from dying of a whole host of diseases, including stroke, certain cancers, and diabetes.<sup>113</sup> The Centers for Disease Control and Prevention report that cancer death rates for women are highest among African Americans, followed by Caucasians, Hispanics, and Asian/Pacific Islanders. Cancer has been the leading cause of death for female Asian Americans since 1980.<sup>114</sup>

Race affects the quality of health care minority patients are given.<sup>115</sup> Unfortunately, there is proven racial bias in the practice of health care.<sup>116</sup> The source of this “pervasive, often subtle discrimination,” is often difficult to determine.<sup>117</sup> Some of the discrimination is caused by providers who discriminate against certain races and also the lack of access to providers in African American communities.<sup>118</sup> Additionally, African Ameri-

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110. See *id.* at 97.

111. See Kenneth D. Kochanek et al., *Deaths: Final Data for 2009*, NAT'L VITAL STATS. REPS., Dec. 29, 2011, at 1, 3 (Table A noting that in 2008 and 2009, the life expectancy for whites was higher than for African Americans, and that the infant mortality rates for African American infants was double the infant mortality rates for whites during the same period).

112. See Lisa A. Cooper & Debra L. Roter, *Patient-Provider Communication: The Effect of Race and Ethnicity on Process and Outcomes of Healthcare*, in *UNEQUAL TREATMENT: CONFRONTING RACIAL AND ETHNIC DISPARITIES IN HEALTH CARE* 552, 570 (Brian D. Smedley et al. eds., 2003).

113. Office of Minority Health, *Health Disparities Experienced by Black or African Americans—United States*, CDC (Jan. 14, 2005), reprinted in 293 JAMA 922 (2005).

114. See *id.*

115. See Barbara Noah, *The Role of Race in End-of-Life Care*, 15 J. HEALTH CARE L. & POL'Y 349, 351 (2012). See also CARA JAMES ET AL., HENRY J. KAISER FAMILY FOUND., KEY FACTS: RACE, ETHNICITY, & MEDICAL CARE 7–12 (2007), available at <http://www.kff.org/minorityhealth/upload/6069-02.pdf> (documenting the prevalence of health disparities by condition, insurance status, and utilization of primary and preventive care and specialist care).

116. See JAMES ET AL., *supra* note 112.

117. M. Gregg Bloche, *Race and Discretion in American Medicine*, 1 YALE J. HEALTH POL'Y L. & ETHICS 95, 98 (2001).

118. Vernellia R. Randall, *Slavery, Segregation, and Racism: Trusting the Health Care System Ain't Always Easy! An African American Perspective on Bioethics*, 15 ST. LOUIS U. PUB. L. REV. 191, 210–12 (1996).

cans have higher rates of hospitalization and death in part structural racial bias.<sup>119</sup>

Also, class has an effect on cancer survival. Cancer has a disproportionately severe impact on the poor. More often than not, minorities are likely to be poor. A Pew Research Center study noted that “[t]he median wealth of white households is 20 times that of black households and 18 times that of Hispanic households,”<sup>120</sup> the largest gap since the government began publishing this information.<sup>121</sup> Some of the disproportionate impact has been attributed to delayed diagnosis as well as poor patient care. Poor people who lack health insurance or have inadequate access to quality cancer treatment also experience higher cancer incidence, higher mortality rates, and lower survival rates than their more well off counterparts.<sup>122</sup>

When focusing specifically on reproductive health and fertility preservation for medical reasons, the obvious issue is infertility. Infertility is a problem that affects all races, but Blacks have lower fertility rates than other races after the age of twenty-five.<sup>123</sup> Nevertheless, women of color are significantly less likely to seek aid to help their infertility.<sup>124</sup> Below under the reproductive rights discussion, I delve into the effects of this lack of access.

### *Fertility Preservation for Medical Reasons and Reproductive Rights*

The reproductive rights component in this reproductive justice analysis is a legal-advocacy based model designed to protect women’s access to reproductive health care at the state and federal levels.<sup>125</sup> Black women have much lower rates of use of ART than other races.<sup>126</sup> This appears to be based on lack of insurance coverage and lack of access. Fertility clinics seem to recognize this. One study on fertility clinics’ websites noted that 62.93% of fertility clinic websites examined had pictures of only white babies.<sup>127</sup> Critics of ART have deemed the “technology largely reserved

119. See Ruqaiyah Yearby, *Racial Inequities in Mortality and Access to Health Care*, 32 J. LEGAL MED. 77, 90 (2011). See also Council on Ethical & Judicial Affairs, Am. Med. Ass’n, *Black-White Disparities in Health Care*, 263 JAMA 2344, 2344 (1990) (stating that though African Americans need to access health care more than others, they have less of a chance of obtaining the required services).

120. See Noah, *supra* note 112, at 350.

121. See Yearby, *supra* note 119.

122. See *id.*

123. June Carbone, *If I Say “Yes” to Regulation Today, Will You Still Respect Me in the Morning?*, 76 GEO. WASH. L. REV. 1747, 1749 (2008).

124. Janelle Richards, *Cost and Culture Keeping Black Women out of Infertility Centers*, THE GRIO (Mar. 10, 2011, 8:16 AM), <http://www.thegrio.com/health/cost-and-culture-keeping-Black-women-out-of-infertility-centers.php>.

125. This component protects woman’s reproductive rights by protecting her right to privacy, her right to make choices, her right to be free from discrimination, her right to access services and her actual access to social resources. Discussions of reproductive rights in the U.S focus primarily on keeping abortion legal and increasing access to family planning services.

126. See Noah, *supra* note 115.

127. See Jim Hawkins, *Selling ART: An Empirical Assessment Of Advertising On Fertility Clinics’ Websites*, 88 IND. L.J. 1147, 1169 (2013).

for the wealthy and the White,” even though a disproportionate number of infertile women in this country are Black.<sup>128</sup> Scholar David Orentlicher has noted that when health insurance does not cover infertility treatments and couples (or individuals) must pay out of pocket, then “the significant costs of these treatments mean that they tend to be reserved for wealthier, white couples who can pay for them out of personal resources.”<sup>129</sup> Increased rates of infertility and less access to ART means that minority populations have to live with the consequences of infertility while others do not.<sup>130</sup>

The Affordable Care Act (ACA) increases the number of people who will have access to health insurance, so this could help even the playing field in terms of health outcomes for minority cancer patients. However, the ACA does not require states to cover IVF, fertility preservation, or other forms of ART. To protect the reproductive rights of poor and minority cancer patients, it may be necessary to require such insurance coverage. This lack of ART coverage seems to be based upon insurance status and cost.<sup>131</sup> For reproductive fairness, insurers and the federal government are in a better position to bear the cost burden of ART services rather than poor or minority cancer patients. In past cases, when the cost barrier to care was substantially lessened or eliminated, such as when Blacks joined the military and enjoyed healthcare coverage for ART, utilization of fertility treatment by African Americans became proportional and underutilization less of a problem.<sup>132</sup>

### *Property Rights in Fertility Preservation for Medical Reasons*

There are numerous other legal issues affecting reproductive rights that must be addressed if fertility preservation becomes more common. Just as in other areas of ART, there will be disputes over the ownership, use, and disposal of tissues, eggs, sperm, and embryos. In most ART, there are concerns about how stored bodily material (gametes, embryos, gonads, gonadal tissue) will be used and disposed of.<sup>133</sup> However, in fer-

128. See Kimberly M. Mutcherson, *Transformative Reproduction*, 16 J. GENDER RACE & JUST. 187, 222 (2013).

129. Orentlicher, *supra* note 50, at 181.

130. See Marcia C. Inhorn & Michael Hassan Fakh, *Arab Americans, African Americans, and Infertility: Barriers to Reproduction and Medical Care*, 85 FERTILITY & STERILITY 844, 845 (2006). See also Eve C. Feinberg et al., *Comparison of Assisted Reproductive Technology Utilization and Outcomes Between Caucasian and African American Patients in an Equal-Access-to-Care Setting*, 85 FERTILITY & STERILITY 888, 890 (2006); Maurizio Macaluso et al., *A Public Health Focus on Infertility Prevention, Detection, and Management*, 93 FERTILITY & STERILITY 16.e1, 16.e2 (2010).

131. See Feinberg et al., *supra* note 124, at 889.

132. See *id.* at 893.

133. See Sarah Rodriguez et al., *Fertile Future? Potential Social Implications of Oncofertility*, 31 J. OF CLINICAL ONCOLOGY 665, 665–67 (2013). It has been noted that future use and disposal of gonads and gonadal tissue are different than use and disposal of embryos and gametes, depending upon whether gonads and gonadal tissue is classified as organs or as gametes. See *id.* There needs to be additional thought to what type of classification makes the most sense to avoid court disputes and moral dilemmas. See *id.* If such materials are classified as organs, they may be subject to allocation rules under the United Network of Organ Sharing. See *id.*

tility preservation for medical reasons, the primary purpose of extracting these materials is to store them for the future, especially in the case of children with such diseases who may not use their preserved materials for several years.<sup>134</sup> Also, because those involved are cancer patients, they have an increased likelihood of death than other ART patients.<sup>135</sup> So issues of disposition and ownership are even more important in this population because they are sick and more likely to die than others who are using ART.<sup>136</sup> Cases regarding property rights in frozen embryos are commonplace in ART, and they are becoming more common in oncofertility cases.<sup>137</sup>

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134. See *id.* at 665.

135. See *id.*

136. See *id.*

137. In another disposition case, *Szafranski v. Dunston*, the Circuit Court of Cook County, Illinois originally granted Dunston (the ex-girlfriend) summary judgment and full custody of pre-embryos she created with Szafranski (the ex-boyfriend). *Szafranski v. Dunston*, 993 N.E.2d 502, 503 (Ill. App. Ct. 2013). Szafranski appealed, claiming that summary judgment was inappropriate as there were still issues of fact to resolve, and that his consent was required to use those pre-embryos under the privacy and liberty rights of both the United States and Illinois Constitutions. See *id.* The embryos were created when Dunston asked Szafranski to donate his sperm in order to create embryos following her diagnoses of non-Hodgkin's lymphoma and subsequent chemo treatments. See *id.* When the couple met with doctors to deposit the sperm, they signed an informed consent form that stated, "[n]o use can be made of these embryos without the consent of both partners (if applicable)," as well as a disclaimer regarding the unsettled state of the law regarding in vitro fertilization. *Id.* at 504. After meeting with an attorney, a co-parent agreement was drafted, but never signed. See *id.* It indicated that they would both be legal co-parents of any children that resulted from their embryos. See *id.* This agreement specifically stated that Szafranski "agrees to undertake all legal, custodial, and other obligations to the Child regardless of any change of circumstance between the Parties," and that "[s]hould the Intended Parents separate, Karla will control the disposition of the pre-embryos." *Id.* Shortly after three viable embryos were created, the couple ended their relationship, and Szafranski filed a complaint in circuit court to enjoin Dunston from using the pre-embryos. See *id.* at 504–05. The Circuit Court granted Dunston's motion for summary judgment and denied Szafranski's motion for summary judgment, giving Dunston "full custody and control over the disputed pre-embryos . . . and [stating that she] may use them to attempt to have children." *Id.* at 506. Szafranski appealed, and the Court considered the issue of first impression of "who controls the disposition of cryopreserved pre-embryos created with one party's sperm and another party's ova." *Id.* The Court noted that there are three ways to approach this issue: (1) a contractual approach, (2) a contemporaneous mutual consent approach, and/or (3) a balancing approach. See *id.* Each party argued for a different approach, and the Court ultimately chose to honor the mutually expressed intent of the parties, as set forth in prior agreements (the contract approach), reasoning that this "properly allows them, rather than the courts, to make their own reproductive choices while also providing a measure of certainty necessary to proper family planning." *Id.* at 515. The Court also believed that this will encourage couples to seriously discuss their "desires, intentions, and concerns" with each other before participating in in vitro fertilization. *Id.* The Court further held that "where there has been no advance agreement regarding the disposition of pre-embryos, 'then the relative interests of the parties in using or not using the preembryos must be weighed.'" *Id.* The Court found no basis for Szafranski's constitutional arguments and dismissed them. See *id.* at 516–17. The Court then remanded the matter to the Circuit Court with an order to apply the contract approach to the facts/evidence at hand. See *id.* at 517–18.

To protect the cancer patient, there should be a clear agreement of who owns the biological material and what will happen to it should the patient die. One can imagine a truth-is-stranger-than-fiction scenario where a grieving mother may wish to use a surrogate, or worse implant in her own womb, her child's preserved eggs in order to have a posthumously conceived grandchild. With greater access to technology comes the reality that the unreal can and may happen. One must ensure that the parent is making the decision to preserve a child's reproductive potential with the best interests of the child in mind, not as a back-up grandchild. It is difficult to draw hard and fast rules but allowing for the tissue or eggs to be donated or destroyed in the case of the patient's death should be agreed upon in advance to avoid the crazy stories that ART sometimes brings.

Garden variety cases that come up any time eggs or embryos are formed have come up in fertility preservation for medical reasons cases as well. Ownership of embryos created for the purpose of fertility preservation should be clearly delineated at the time of the embryo creation to avoid legal wrangling and unjust results. For example, in one case, a husband and wife created thirteen pre-embryos after finding out that the wife had breast cancer.<sup>138</sup> The wife underwent two surgeries, eight rounds of chemo, and thirty-seven rounds of radiation, making her unable to have children.<sup>139</sup> The couple divorced and the divorce court awarded the pre-embryos to the wife, reasoning, "that the pre-embryos are marital property subject to equitable distribution."<sup>140</sup> The lower court applied a balancing test, finding that the "Wife's inability to achieve biological parenthood without the use of the pre-embryos is an interest which outweighs [the] Husband's desire to avoid procreation."<sup>141</sup> While the couple did sign an informed consent form for storage of the pre-embryos stating that storage was not to exceed three years, the Court interprets this as an agreement between the couple and the storage company, *not* an agreement between the husband and wife to destroy the pre-embryos at that point.<sup>142</sup>

The Superior Court then considered whether the lower court properly applied the balancing standard. The Court ultimately agreed with the lower court that, "because [the] Wife cannot achieve genetic parenthood otherwise . . . [the] Wife's interest in biological procreation through the

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138. See *Reber v. Reiss*, 42 A.3d 1131, 1132–33 (Pa. Super. Ct. 2012).

139. See *id.* at 1133.

140. *Id.*

141. *Id.* at 1134. (quoting the lower court's opinion). The Superior Court of Pennsylvania reviewed the husband's appeal for abuse of discretion, ultimately affirming the lower court's order. See *id.* The Court notes there are three approaches (contract, contemporaneous mutual consent, and balancing) to resolving the issue of first impression surrounding "the contested disposition of frozen pre-embryos in the event of divorce." *Id.* The Court reasoned that it does not need to adopt one approach over another, because the lower courts applied the balancing test in the absence of a signed provision related to the pre-embryos in the event of divorce, and the husband and wife could not come to a contemporaneous mutual agreement. See *id.* at 1136.

142. See *id.* at 1336.

use of these pre-embryos outweighs [the] Husband's professed interest against procreation."<sup>143</sup> While the husband argued that the wife could become a mother through different means (adoption or being a foster parent), in relation to balancing the wife's interest, the Court stated that,

There is no question that the ability to have a biological child and/or be pregnant is a distinct experience from adoption. Thus, simply because adoption or foster parenting may be available to [the] Wife, it does not mean that such options should be given equal weight in a balancing test. Adoption is a laudable, wonderful, and fulfilling experience for those wishing to experience parenthood, but there is no question that it occupies a different place for a woman than the opportunity to be pregnant and/or have a biological child.<sup>144</sup>

The Court ultimately found that the wife had a compelling interest in using the pre-embryos to have a baby because they are "likely her only chance at genetic parenthood and her most reasonable chance for parenthood at all."<sup>145</sup> The Court found that this interest superseded the husband's interest in this case.<sup>146</sup> The Court also rejected the husband's argument that he only agreed to create the pre-embryos as a "safeguard," and that he never actually planned on having a baby with the wife.<sup>147</sup> The Court stated that the only reason someone would undergo in vitro fertilization is to have a child, and that his participation in the process shows that he clearly understood that a potential child would result from it.<sup>148</sup> The Court finally dismissed the husband's argument that "it is against Pennsylvania public policy to force him to procreate with [his] Wife when he does not want to do so," as never being addressed by the Pennsylvania courts.<sup>149</sup> The Court ultimately agreed with the trial court that in balancing all of these factors, the scale tips in the wife's favor.<sup>150</sup> Even in the reasoning of this case, which relates to the ownership of the embryos, one sees the preference given towards the ability to have a biologically related child.

### *Fertility Preservation for Medical Reasons and Reproductive Fairness*

In this section, I explore how reproductive fairness can be achieved for patients facing infertility due to medical reasons. In this section, I attempt to theorize how to organize individuals and communities to create structural change and challenge power inequalities that this population is facing. "Reproductive fairness" includes social justice for entire communities, and requires a complete vision of health for women and girls including an understanding of issues such as sex trafficking, youth empowerment, women's health, family well-being, educational justice,

143. *Id.* at 1137 (quoting the lower court's opinion).

144. *Id.* at 1138–39.

145. *Id.* at 1140.

146. *See id.*

147. *Id.*

148. *See id.*

149. *Id.* at 1142.

150. *See id.*

unsafe working conditions, domestic violence, immigration injustices, environmental racism, and globalization.<sup>151</sup> This section is intended to be a starting point for the generation of “new patterns of thinking” and to offer a “fresh approach to creating unifying and intersectional language”<sup>152</sup> with which to build bridges across racial and class fissures that prevent productive conversations on race, rights and reproduction.

### *Gaining Trust*

One important issue to consider when trying to empower vulnerable cancer patients with information and potential access to fertility preservation services is trust. Trust is gained by true and detailed informed consent—which includes discussions of a physician’s competing loyalties (for example, if he or she is being paid to be part of an experimental protocol.) Many minorities and immigrants may distrust the medical system and experimental therapies due to the United States’ haunting history of treating minorities as guinea pigs without their consent.<sup>153</sup> Slaves in the United States were often used in medical experimentation without knowledge or consent.<sup>154</sup> One particularly horrifying incident occurred when one doctor performed multiple painful surgeries without using anesthesia on slave women who suffered from vesico-vaginal fistula.<sup>155</sup> The Tuskegee syphilis experiment has gained notoriety because the United States Public Health Services experimented on 400 poor Black men with syphilis for over forty years in which they were never told they had the disease and denied proper medical treatment, even when it was readily available.<sup>156</sup> Less well known are two studies, one occurring in 1963 in which doctors injected live cancer cells into twenty-two chronically ill, poor African American women without their consent or knowledge, and another study of twenty women who were primarily poor, young and Black on an experimental medical device used to induce abortions despite general consensus in the medical community that this device should not be used.<sup>157</sup> Such a history has often caused African Americans to distrust medical research and the medical community in general. But members of several groups share this history. For example, a medical experiment on Latino boys on psychiatric drugs has contributed to decreased trust in the Latino community in the medical profession.<sup>158</sup> Asians have similarly suf-

151. Loretta Ross, *Understanding Reproductive Justice: Transforming the Pro-Choice Movement*, 56 (4) *Off Our Backs* 14, 14 (2007).

152. *See id.*

153. Randall, *supra* note 115, at 191 (noting that many African Americans fear and distrust the health care system as a result of historical abuses, which reflects their views of the system).

154. *See* TODD L. SAVITT, *MEDICINE AND SLAVERY: THE DISEASES AND HEALTH CARE OF BLACKS IN ANTEBELLUM VIRGINIA* 293 (1978).

155. *See id.*

156. *See* JAMES H. JONES, *BAD BLOOD: THE TUSKEGEE SYPHILIS EXPERIMENT* 5–9 (1993).

157. Alvis V. Adair, *Human Experiment: An Ancient Notion in a Modern Technology*, INST. FOR URBAN AFFAIRS AND RESEARCH, HOWARD UNIV., 1974, at 1, 9–10.

158. *See* Marianne Engelman Lado, *Unfinished Agenda: The Need for Civil Rights Litigation to Address Race Discrimination and Inequalities in Health Care Delivery*, 6 *TEX. F. ON C.L. & C.R.* 1, 11 (2001).



ferred worse health outcomes due to discriminatory practices in health care delivery.<sup>159</sup> The poor and immigrants have been experimented upon many times.<sup>160</sup> This history contributes to distrust of doctors by members of minority communities.<sup>161</sup> Because many of the fertility preservation techniques are indeed experimental, there must be an effort to ensure that the poor and uneducated and minority patients are protected.

Another point to consider when examining fertility preservation for medical reasons through a reproductive justice framework is to consider the history of sterilization of Black women, often with the assistance of public funding or in public hospitals.<sup>162</sup> Black's Law Dictionary defines "sterilization" as "[t]he act of making (a person or other living thing) permanently unable to reproduce."<sup>163</sup> Not informing Black women of their reproductive options while undergoing cancer therapy can be seen as a "softer" form of sterilization, especially if Black women are not informed of their fertility preservation options as often as other races. The lack of trust that the history of sterilizations brings must be addressed, and giving patients detailed, consistent information may help garner more trust.

This history has resulted in a skepticism and distrust of medical care and medical interventions by the Black community. Physicians must be sensitive to this potential and spend time with Black patients explaining fertility preservation. The studies cited earlier show that physicians are often not even addressing fertility preservation with minority patients. This is a problem because it could be seen as the medical community further limiting reproductive rights of Blacks. This must be balanced with the fact that these technologies are in their infancy, and there is a fear of experimentation within this community. Physicians must be forthright in the fact that fertility preservation does contain physical risks

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159. See generally ANNE FADIMAN, *THE SPIRIT CATCHES YOU AND YOU FALL DOWN: A Hmong Child, Her American Doctors, and the Collision of Two Cultures* (1997); see also Rose Cuison Villazor, *Community Lawyering: An Approach to Addressing Inequalities in Access to Health Care for Poor, of Color and Immigrant Communities*, 8 N.Y.U. J. LEGIS. & PUB. POL'Y 35, 39 (2005) (describing discrimination in healthcare, medical care and medical facilities based on race, ethnicity and language).
  160. See DIANA SCULLY, *MEN WHO CONTROL WOMEN'S HEALTH: THE MISEDUCATION OF OBSTETRICIAN-GYNECOLOGISTS* 45 (1980) (describing how a New York Women's Hospital engaged in surgical experimentation on impoverished immigrant women new to New York City in the mid-1800s); see generally DEBORAH KUHN MCGREGOR, *SEXUAL SURGERY AND THE ORIGIN OF GYNECOLOGY: J. MARION SIMS, HIS HOSPITAL, AND HIS PATIENTS* (1989) (describing how doctors performed medical experiments on poor women).
  161. See Irena Stepanikova et al., *Patients' Race, Ethnicity, Language, and Trust in a Physician*, 47 J. HEALTH & SOCIAL BEHAV. 390, 401 (2006) (noting that minority patients' knowledge of a history of discrimination in healthcare may decrease their confidence in doctors); see also William D. King, Comment, *Examining African Americans' Mistrust of the Health Care System: Expanding the Research Question*, 118 PUB. HEALTH REPS. 366, 366 (2003); see also Giselle Corbie-Smith, *Distrust, Race, and Research*, 162 ARCHIVES INTERNAL MED. 2458, 2459-60 (2002) (concluding that African Americans were significantly more likely than whites to believe that their doctors would not fully disclose the risks of research participation).
  162. See ANGELA Y. DAVIS, *WOMEN, RACE AND CLASS* 215-21, 216 (1981).
  163. Black's Law Dictionary 717 (4th ed. 2006).

and is not a guarantee, and also open a dialogue with a minority patient about the process of preservation and the potential of IVF in the future. An additional part of the problem has been that minorities are diagnosed with cancer at a later stage, and there is less time to consider fertility preservation. Better health care and health equity for all will help alleviate this disparity and ensure doctors also have enough time to consider fertility preservation for this population. Some have suggested that given the fast pace change in the science of fertility preservation, a specialized team, rather than just an oncologist, may be needed to provide fertility preservation information.<sup>164</sup>

### *Increasing Health Literacy*

In addition to trust, in order to have true reproductive justice in fertility preservation for medical reasons, the health literacy of all populations must be enhanced through education and detailed, simplified informed consent.<sup>165</sup> Health literacy means the ability to obtain, understand, and utilize health information to make sound health decisions.<sup>166</sup> Thus, informed consent forms that are written in language above the average patient's reading level fail the health literacy standard.<sup>167</sup> Someone must discuss the informed consent standards related to fertility preservation for medical reasons and not just hand a vulnerable patient a form. Also, language barriers and technological barriers may be a problem for those encountering the health care system.<sup>168</sup> Thus, for those who may have difficulty understanding English, translation of materials and conversations is important for true health literacy.

### *The Goal of Biological Parenthood*

Another reproductive justice issue to consider with fertility preservation for medical reasons is whether it reinforces the ultimate goal of biological parenthood.<sup>169</sup> Dorothy Roberts has written on fertility

164. Jennifer Levine et al., *Fertility Preservation in Adolescents and Young Adults with Cancer*, 28 J. CLINICAL ONCOLOGY 4831, 4831 (2010).

165. Brietta Clark, *Using Law to Fight a Silent Epidemic: The Role of Health Literacy in Health Care Access, Quality, and Cost*, 20 ANNALS HEALTH L. 253, 257–58, 284 (2011).

166. See *id.* at 258.

167. See Ad Hoc Comm. on Health Literacy for the Council on Scientific Affairs, Am. Med. Ass'n, *Health Literacy: Report of the Council on Scientific Affairs*, 281 JAMA 552, 553–54 (1999).

168. See Mark V. Williams et al., *Inadequate Functional Health Literacy Among Patients at Two Public Hospitals*, 274 JAMA 1677, 1679–80 (1995) (noting that approximately 30 percent of English-speaking patients in one study location could not understand simple written health instructions); see, e.g., HENRY J. KAISER FAMILY FOUND., *THE DIGITAL DIVIDE AND ACCESS TO HEALTH INFORMATION ONLINE*, (2011), available at <http://www.kff.org/kaiserpolls/upload/8176.pdf> (noting that, although the gap is somewhat closing, racial and ethnic disparities in computer and Internet access remain substantial and that these disparities foreclose opportunities to access health information online).

169. See Shauna L. Gardino & Linda L. Emanuel, *Choosing Life When Facing Death: Understanding Fertility Preservation Decision-Making for Cancer Patients*, in *ONCOFERTILITY: ETHICAL, LEGAL, SOCIAL, AND MEDICAL PERSPECTIVES* 447, 447 (Teresa K. Woodruff et al. eds., 2010).

preservation for medical reasons and has noted that technological solutions to social problems often result in further oppressing already-disadvantaged groups.<sup>170</sup> Roberts notes that there is a fine line between informed consent—where patients are informed by oncologists about fertility preservation—to a sort of coercion, where parents of minor patients and adult female patients feel pressured into freezing their eggs because of the chance at biological motherhood.<sup>171</sup> Roberts questions the narrative that fertility preservation improves the reproductive rights of all women. In fact, the physical risks of the fertility preservation egg retrieval or tissue retrieval and the potential delay in cancer therapy should be assessed critically. Because Black women are often treated later in their cancer progression, any delay may negatively impact their survival chances. Also parents of cancer patients should not be made to feel like they are somehow sterilizing their child by choosing not to preserve their child's reproductive tissue. There needs to be an informed consent discussion that takes the time to consider all the options. While the AMA and OSCO policies suggesting the discussion of fertility preservation are laudable in increasing options for patients, the standard of care should include a full discussion of reproductive options after cancer treatment. As mentioned earlier, studies have shown that some women regain their reproductive potential naturally after cancer treatment.<sup>172</sup>

Adoption is another option that should be included in a discussion of reproductive justice. Just because it is theoretically possible to preserve a woman's fertility, it is not a sure thing. In fact, except for egg or sperm freezing, which can only occur in post pubescent patients and has resulted in live births, the other fertility preservation techniques have resulted in less than a handful of live births. Relying on the marvels of fertility preservation alone during post cancer treatment may not be a wise choice. The medical community should be trained to discuss alternatives to biological parenthood, such as adopting a child. To be sure, not every woman must be a mother at all, but given the history of limiting minority mothering rights, I err on the side of aiding in all forms of motherhood, rather than acknowledging that one can have a happy fulfilled life without being a parent. The "medical miracle" of fertility preservation for medical reasons should not mean that improving access to other avenues of parenthood should be abandoned. Adoption is a long, expensive, and exclusive process in the United States, and even more so for cancer survivors.<sup>173</sup> Adoption is often only an option to healthy, married young couples.<sup>174</sup> Some adoption agencies indicate that the number of disease-free years is a relevant consideration while others are simply unaware of the importance of the information.<sup>175</sup> Just because fertility preser-

170. See Dorothy E. Roberts, *The Social Context of Oncofertility*, 61 DEPAUL L. REV. 777, 797 (2012).

171. See *id.* at 783.

172. See Green, *supra* note 37.

173. Shauna L. Gardino et al., *Adoption After Cancer: Adoption Agency Attitudes and Perspectives on the Potential to Parent Post-Cancer*, CANCER TREAT RES., 2010, at 153, available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3086473/>.

174. See *id.*

175. See *id.*

vation technology exists and could be made use of may actually worsen the bias against adoption by those with cancer in their pasts. As one scholar suggests, fertility preservation for medical reasons should really be regarded not as “preserving the possibility of motherhood” but rather “increasing the number of paths to motherhood from which a woman might later choose.”<sup>176</sup> Dorothy Roberts notes that several psychological studies show that infertile people who adopt children have levels of well being similar to those who succeed with fertility treatments.<sup>177</sup> However, is it just to deny these procedures to poor and minority women when affluent women who can afford it have access to them? Just because studies show that women are happy adopting, should the medical community and society just pat poor and minority women on the back and say, “Don’t worry, you can always adopt”? It does not seem fair to deny biological motherhood on the basis of wealth. Roberts’s criticisms should be taken into account, but there are ways to allow women access to have a biological child, without making biological motherhood a normative ideal. More options, rather than less, seems to be a better road to reproductive justice. One of the ways to do is to move towards a model of informed consent that does not make value judgments of biological motherhood as being preferential to another type of parenthood or perhaps not becoming a parent.

### *Informed Consent Under a Reproductive Justice Model*

Art Caplan, a noted bioethicist, has argued that as long as the standards of informed consent are met, offering fertility preservation services to cancer patients may be appropriate even though these involve experimental treatments.<sup>178</sup> Given the history of experimentation and justifiable distrust of the medical and research communities by members of minority communities, this section attempts to define what appropriate informed consent for fertility preservation for medical reasons would look like in a reproductive justice model. Our modern notions of informed consent stem from the classic 1972 case *Canterbury v. Spence*,<sup>179</sup> which adopted a patient centered model of informed consent. Because studies have shown that African American cancer patients are not informed of fertility consequences of cancer treatment compared with other patients,<sup>180</sup> it is important to ensure that the standard of care is to inform all patients of the risks to fertility of cancer treatment itself. Just because a patient already has children or is under- or uninsured should not affect

176. Christina L. H. Traina, *Ovarian Tissue Cryopreservation and Bioethical Discourse*, in *ONCOFERTILITY: ETHICAL, LEGAL, SOCIAL, AND MEDICAL PERSPECTIVES* 171, 173, 177 (Teresa K. Woodruff et al. eds., 2010).

177. See Roberts, *supra* note 165, at 790 (citing Carolyn McLeod, *Morally Justifying Oncofertility Research*, in *ONCOFERTILITY: ETHICAL, LEGAL, SOCIAL, AND MEDICAL PERSPECTIVES* 187, 191).

178. See Pasquale Patrizio & Arthur L. Caplan, *Ethical Issues Surrounding Fertility Preservation in Cancer Patients*, 53 *CLINICAL OBSTETRICS & GYNECOLOGY* 717, 718 (2010).

179. 464 F.2d 772, 780 (D.C. Cir. 1972) (“Every human being of adult years and sound mind has a right to determine what shall be done with his own body . . . .”) (quoting *Schloendorff v. Soc’y of N.Y. Hosp.*, 105 N.E. 92, 93 (N.Y. 1914)).

180. See Shnorhavorian, *supra* note 54.

the information that the patient receives about fertility preservation options and availability. Patients should receive information about the risks of the options to the patients and potential risks to the offspring conceived through ART. They should also receive information about the cost of this option and whether their insurance will cover it. Additionally, a physician should fully disclose any financial interests or conflicts of interest that he or she may have. These could include being an investigator as part of an experimental fertility preservation study or protocol or having a financial interest in any cryopreservation business or storage facility. One can see how this conflict of interest may affect how positive an assessment a physician gives fertility preservation. Additionally, because of the disparities in cancer treatment success rates and survival rates between races, a physician must realistically disclose the impact of fertility preservation on the cancer treatment regimen itself. Also, because this is a new field, physicians should not give false hope to patients who already are vulnerable due to their diagnosis. They should give realistic statistics about the potential success of fertility preservation options. At the same time, they should present information about adoption as an option but also inform patients about the roadblocks they may face adopting as a cancer survivor. The ASCO policy of informing patients about fertility preservation should be amended to acknowledge racial and demographic disparities that exist in informing patients about fertility preservation and recommend that physicians disclose this option to all patients, regardless of race and prognosis. To be sure, someone with a Stage IV cancer diagnosis may be more worried about his or her own survival than fertility preservation, but that should be a decision for that patient to make. The process of informed consent and fertility preservation discussion educates patients and helps them be more empowered navigating through the medical system. Especially in minority populations, where people may not feel as comfortable within the medical system, a robust discussion involving the patient's options may go a long way in gaining some trust in the system, regardless of whether one chooses to undergo fertility preservation. If such a discussion results in more minorities seeking fertility preservation or at least feeling more in control of their health and future, this would be a step towards regaining trust in the medical system.

Informed consent is also complicated when a parent is consenting for a mature child or adolescent. Especially in the case of adolescents, they should be made part of the informational process related to fertility preservation and their feelings on the subject should be taken into account.

### *Reproductive Justice and Lack of Health Insurance Coverage*

Whenever fertility preservation for medical reasons is discussed, the high costs of the procedures used to preserve fertility must be acknowledged.<sup>181</sup> Who should pay for the preservation of these materials? The

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181. See JAMES ET AL., *supra* note 112, at 7–12 (noting that insurance status and socioeconomic status contribute to poorer overall health status for racial and ethnic minority groups).

AMA policy and the California bill advocate for insurance companies to cover fertility preservation for medical reasons services. Some scholars argue that even if insurance companies do not cover other forms of ART, they should cover fertility preservation for medical reasons services because it does not differ from other treatments for iatrogenic conditions currently covered for patients with cancer. Under a reproductive justice framework, it is important to consider whether this is the wisest use of health care resources given that only 10% of cancers affect those younger than 45.<sup>182</sup> Also, the success rates of fertility preservation efforts are modest at best right now. True, they may get better if there were more participation—which insurance coverage may guarantee—but perhaps the money would be better spent helping poor and minority communities gain better access to health care. Without insurance coverage, those who are able to pay for fertility preservation for medical reasons will likely be the same population that accesses ART: white, educated, middle- and upper class.<sup>183</sup> However, some note that the lack of insurance coverage for fertility techniques has profoundly limited access to care for underserved populations. If the ability to have a biological child is a right,<sup>184</sup> arguably these technologies should be made available to all individuals experiencing infertility, including those patients facing fertility-threatening therapies.<sup>185</sup> At the heart of class issues in fertility preservation for medical reasons lies the fact that fertility preservation, and specifically the harvesting and storage of eggs, is expensive.<sup>186</sup> Low-income women and those facing poverty are often unable to use any of these services,<sup>187</sup> and the factors bearing directly on that class of women include race, education level, and marital status.<sup>188</sup> The question then becomes whether subsidizing fertility preservation will help to reduce the economic disparities in availability of fertility treatments or whether it will simply privilege those who are already the most advantaged.<sup>189</sup>

One argument against such subsidies and the continued funding of such research and innovation notes that while economic disparities and barriers are unfortunate, they do not justify interfering with the rights of

182. See Basco et. al., *supra* note 89, at 835.

183. See Rodriguez et al., *supra* note 127, at 666; see also Tarun Jain, *Socioeconomic and Racial Disparities Among Infertility Patients Seeking Care*, 85 FERTILITY AND STERILITY 876, 879–80 (2006) (noting that even in states with mandated infertility coverage, significant racial disparities exist with regards to seeking infertility care).

184. See John A. Robertson, *Procreative Liberty and Harm to Offspring in Assisted Reproduction*, 30 AM. J.L. & MED. 7, 19 (2004) (noting that the right to have children is a widely accepted personal liberty).

185. See Rodriguez et al., *supra* note 127, at 666 (noting arguments that “insurance companies should cover oncofertility (even if they do not cover other forms of ART), because it does not differ from other treatments for iatrogenic conditions currently covered for patients with cancer”).

186. See Roberts, *supra* note 165, at 790. Tissue cryopreservation costs average \$30,000, while IVF cycles cost approximately \$15,000 and live births from these procedures cost greater than \$40,000. See *id.*

187. See *id.*

188. See *id.* (citing Mary Lyndon Shanley & Adrienne Asch, *Involuntary Childlessness, Reproductive Technology, and Social Justice: The Medical Mark of Social Illness*, 34 SIGNS 851, 856 (2009)).

189. See Roberts, *supra* note 165, at 791.

those who are already fortunate enough to be able to use such technologies.<sup>190</sup> The argument is that simply because a person has the right to ART does not obligate the government to provide that ART.<sup>191</sup> Although some may argue that medical innovation may actually increase the class inequality because only the wealthy will be able to afford such new technologies, this seems to be flawed reasoning. Innovation need not be stifled and those that can afford access to medical benefits would not be denied such access.<sup>192</sup> Additional coverage does not take away the rights of those who can afford it outright. Rather, taking Roberts's caution into account, it is possible to have an insurance system that fosters fairness and closes chasms in reproductive health care.

In fact, fertility preservation should be subsidized, and there should be equal access to fertility preservation for medical reasons regardless of wealth.<sup>193</sup> Procreation holds special status in a person's life and has even been deemed by the United States Supreme Court as "one of the basic civil rights of man."<sup>194</sup> Thus, the guarantee of equal protection becomes a compelling reason to ensure access by all to fertility preservation, and the devaluing of the right of historically disadvantaged groups to procreate could be seen as a form of state oppression.<sup>195</sup>

The argument has been made that proposals to mandate insurance coverage of fertility preservation treatments will only serve to enhance the disparities, unless programs to ensure equal access to health insurance itself for low-income and poor patients accompany them.<sup>196</sup> Millions of women must rely on Medicaid for medical care, which covers only those procedures deemed medically necessary.<sup>197</sup> Because fertility preservation is considered to be an elective procedure, only those women fortunate enough to have private insurance would have access, leaving the poorer population in the same position as before mandated insurance coverage.<sup>198</sup>

Another argument is that even if subsidies were provided for low-income women, disparities would still exist in access to types of technology available.<sup>199</sup> Wealthy women would be able to access newer and better technologies and would have the ability to pay for additional services (for example, rather than just one round of IVF, they would be able to afford multiple rounds if needed).<sup>200</sup> In addition, the wealthy may still be the only ones able to afford certain genetic testing and screening.<sup>201</sup> Once the door is opened for subsidies, the question then becomes how much

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190. *See id.*

191. *See id.*

192. *See id.*

193. *See id.*

194. *Id.* (quoting *Skinner v. Oklahoma*, 316 U.S. 535, 541 (1942)).

195. *See id.*

196. *See id.*

197. *See id.* at 791–92.

198. *See id.* at 792.

199. *See id.*

200. *See id.*

201. *See id.*

the public would be willing to support in order to ensure complete equality.<sup>202</sup>

An additional question when considering whether fertility preservation should be subsidized is whether the resources committed would be better spent on other areas.<sup>203</sup> Some argue that the potential millions of dollars would benefit a broader range of the population and would be better spent on research to reduce infertility in general and on the provision of basic health care.<sup>204</sup> However, as fertility preservation for medical reasons continues to grow and new technologies emerge, it does not seem realistic to pick general health care over reproductive health. Rather, access to both needs to be increased, and the public will evaluate the priority given to each.<sup>205</sup> The best answer is to advocate for fertility preservation for medical reasons insurance coverage within a more general health care advocacy, which would improve the lives of the uninsured, the underinsured, and poor minorities. Rather than the AMA policy<sup>206</sup> and the California bill that focus only on fertility preservation alone,<sup>207</sup> the policies of the ACA increasing general health care coverage for more Americans,<sup>208</sup> coupled with policies such as these, will help ensure that all races get their cancers diagnosed at an earlier stage, which would help allow more time for fertility preservation dialogue.

## V. THE FUTURE OF FERTILITY PRESERVATION FOR MEDICAL REASONS

This Article is meant to start a nuanced discussion about fertility preservation for medical reasons and whether promoting it fits with our normative goals as a just, healthy society. This field is just beginning to take shape. There are bound to be more discussions regarding whether to pursue fertility preservation for medical reasons, based on personal convictions and religious beliefs. In addition, legal issues regarding the interplay between parents and a child or adolescent patient in determining the patient's best interests, and how the child or adolescent whose ovarian tissue or gametes were stored will feel about using those materials later will definitely need to be explored.

The reproductive justice framework helps to tease out the issues that still need addressing with fertility preservation for medical reasons. The answer does not seem to be to put a stop to this technology—which is unrealistic and counterproductive. Detailed discussions about fertility preservation for medical reasons will help all groups of patients. There is evidence that patients with cancer who receive counseling about fertility preservation experience less long-term regret than those patients who do not receive counseling, even if the patients choose not to pursue fertility

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202. *See id.*

203. *See id.*

204. *See id.*

205. *See id.* at 792–93.

206. *See* AMA Press Release, *supra* note 62.

207. *See* A.B. 912, 2013–2014 Assemb., Reg. Sess. (Cal. 2013).

208. *See* Janet L. Dolgin & Katherine R. Dieterich, *Social and Legal Debate About the Affordable Care Act*, 80 UMKC L. Rev. 45, 52 (2011) (“The Affordable Care Act expands health care coverage to many people who would not otherwise be protected.”)



preservation.<sup>209</sup> The answer to promoting reproductive justice should not be to withhold available information and existing medical technologies from women, but rather to present all the options to women and make it easier for them to utilize these options. To that end, advocating for better general health care coverage for all Americans and fertility coverage by private and public insurance is extremely important. Instead of fearing that this technology will lead to larger health care disparities, getting all Americans with a higher base level of coverage will ensure that the gaps are narrower and that both of these important goals—health care fairness and reproductive fairness—are achieved. With greater access to health care insurance through the ACA, hopefully cancers will be found earlier, for all races, and with more time to consider fertility preservation as a viable option. If insurers begin covering fertility preservation for these patients, more physicians will likely begin discussing these options to all patients. Such a result would go a long way to close the power and class gap that exists between races and help promote health and reproductive equality.

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209. See Clarisa R. Gracia et al., *Lives in the Balance: Women With Cancer and the Right to Fertility Care*, 31 J. OF CLINICAL ONCOLOGY 1, 1 (2013).

